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Modes of Informed Caring: Perspectives of Health Professionals Who Are Mothers of Adult Children with Schizophrenia

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ABSTRACT

Schizophrenia is a global concern, and, this paper, describes the caring roles of health professionals who are mothers of adult children with schizophrenia. A thematic analysis of data from a doctoral study identified a blending of expertise into an informed care model. Caring roles included: constant carer; coordinator carer; watchful bystander carer; and life coach carer. Previous research has not explored these dual roles. This paper elucidates their responsive approaches and contributions to mothering and caregiving roles. Informed by a fusion of professional and mothering knowledges, their insights into mental health care have been forged by their experiences and is an untapped resource.

Background

As a result of de-institutionalization, people with mental illness live in the community (Raymond et al., 2017) often cared for by family members (Eassom et al., 2014; Dirik et al., 2017; Gutiérrez-Maldonado et al., 2005; Tennakoon et al., 2000). Studies indicate that mothers rather than fathers are usually the primary caregivers for children diagnosed with mental illness such as schizophrenia (Johansson et al., 2015; Papastavrou et al., 2010). Extant research has posited that mothers with dual roles as health professionals have insight into health care provision and are therefore able to evaluate care delivery (Ward-Griffin et al., 2005). A recent study has also found that the insights gained by nurses who care for their family members could potentially contribute to improvement in both the nursing profession as well as the health care system (Quinney et al., 2018). Until recently, there has been a paucity of literature about the experiences of health professionals with dual roles as mothers of adult children with schizophrenia. This paper draws from a broader doctoral study which asked the question “what are the stories that mothers who are health professionals tell of negotiating care within the mental health system for their adult children with schizophrenia?” Findings pertaining to their experiences of mothering in the context of uncertainty-unbalancing and rebalancing as mothers has been reported elsewhere (Klages et al., 2019).

Methods

A qualitative approach informed by feminist insights was selected to examine how health professionals who were

mothers had negotiated care for their adult children with schizophrenia within the mental health system. The study was underpinned by feminist standpoint epistemology which emphasizes the non-neutrality of the researcher and the research process and asserts that women as a marginalized group are able to represent their knowledge and meaning in their lives to advocate for changes within the system (Allen & Jaramillo-Sierra, 2015). The positionality of the interviewer as an ‘insider’ who personally belongs to the group to which the participants also belongs was a factor within the study. Epistemologically, the researcher’s relationship with the participants as an insider, has a direct impact on the knowledge that is co-created between them (Hayfield & Huxley, 2015). A social constructivist (Cottone, 2001) research paradigm guided our feminist storytelling study. In social constructivism, individuals seek understanding and meaning within their lives and the goal of the researcher is to honor the multiplicity of their views (Creswell & Poth, 2017). The research recognizes the precepts of matricentric feminism that “commits to social change and social justice and regards mothering as a socially engaged enterprise and a site of power wherein mothers can and do create social change through childrearing and activism” (O’Reilly, 2016, p. 278). Data collection occurred between November 2017 and July 2018 and included transcripts from the conversational interviews with 13 international health professionals and field notes.

Ethical considerations

Ethics approval was received by the University’s Research Ethics Committee [HE17-028]. Participants were provided

an information sheet which outlined the purpose of the research, the inclusion criteria, as well as information about free of charge (international) support services in the event they required psychological assistance. The participants' confidentiality was guaranteed, whereupon they provided their written informed consent. The research involved self-disclosure of insider status (Berger, 2015) by the first author. The anonymity of the researcher's son was protected by the use of his mother's birth name (different). Her son's rights were respected by disclosing the aims of his mother's doctoral studies and through discussions of her progress.

Participants and recruitment

Participants were recruited through advertisements in mental health professional webpages and electronic messaging lists; social media platforms and in nursing association magazines. A purposive approach to sampling (Patton, 2002) was used to recruit health professionals who were mothers of adult children with schizophrenia. Recruitment was not limited to any specific geographical region and 13 participants, from Australia, Canada, Scotland and the United States agreed to participate. None of the participants had preexisting relationships with the research team. Participants included four mental health nurses, five registered general nurses, one social worker, one occupational therapist, one medical researcher and one medical doctor.

Data collection

Data collection took place via Skype © or in settings which were mutually agreed on by the participants and the interviewer. As previously indicated, prior to commencing each interview, the first author disclosed her positionality as a mental health nurse with a son who has been diagnosed with schizophrenia. Conversational, audio-recorded interviews were undertaken, each lasting approximately one hour. Data collection continued until the interviews yielded no new data and data saturation had been achieved (Saunders et al., 2018). Field notes were taken following each interview.

Data analysis

The audio recordings were professionally transcribed. The first author re-read each transcription whilst listening to the audio recording to ensure accuracy. Transcripts were read several times to become familiar with the data corpus. Reflexive thematic analysis (Braun & Clarke, 2006, 2019), was used to analyze the data and assign initial codes which were then grouped into potential themes. There were regular research team meetings to discuss codes and themes. Themes were tested against the transcripts and adapted until unified themes were identified. During the analysis process, [supplementary data](#) was noticed regarding aspects of care which was being provided by the participants. Consequently, themes were synthesized into a model of informed care.

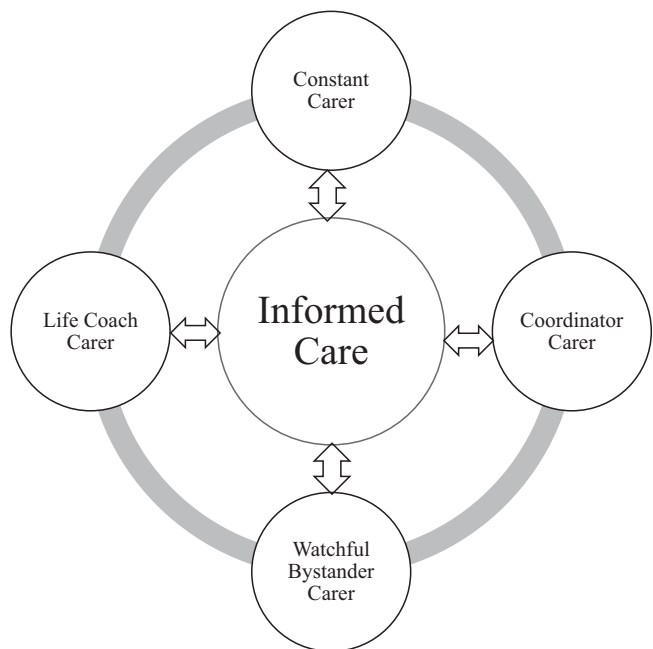


Figure 1. Model of informed care.

Trustworthiness

The trustworthiness and quality of the study was confirmed using the 32-item (Consolidated Criteria for Reporting Qualitative Research) COREQ checklist (Tong et al., 2007). The research team has expertise in qualitative research, and mental health nursing. The potential for social desirability and biases related to insider status was mitigated through ongoing self-reflection and regular discussions of positionality (Berger, 2015) with the research team. The interviewer took field notes throughout the data collection process, recording contextual information impressions, thoughts and reactions (Phillippi & Lauderdale, 2018) to each participant's story.

Findings

This study focused on the mothering experiences of health professionals as they negotiated care for their adult children with schizophrenia within the mental health system. Through the telling of their stories, it became evident that their roles had expanded. They were health professionals and mothers but were also co-producers of an informed model of care. As co-producers of care (Bradley, 2015), their professional and mothering knowledge provided a mechanism by which they contributed to the care of their adult children and the mental health system.

The health professionals' lives changed after their first contact with mental health professionals as mothers. When their two worlds intersected, they used their cumulative resources and professional connections to attempt to access the best care for their children. Their roles as health professionals and mothers were no longer separate entities. Their changing identities and responsibilities synthesized their professional expertise; understanding of organizations and systems as well as their unique knowledge as mothers. The thematic analysis of data-corpus which explicated these

Table 1. Details of the aspects and modes of informed care.

The constant carer		
Focusses on a high level of care		
Aspects of care		
Monitoring: Ensures attendance at appointments, Monitors medication, Monitors their child's mental health status.	Housing: Lives at home.	Professional knowledge: Advocates for their child within the mental health system.
Communication: Communicates with health professionals on a regular basis.	Financial: Provides substantial financial support. Legal: May have legal guardianship.	Mothering: Actively involved in the provision of physical and socio-emotional care on a daily basis.
The coordinator carer		
Focusses on a moderate level of care		
Aspects of care		
Monitoring: Monitors attendance at appointments, Monitors their child's mental health status.	Housing: Lives at home or, In the community	Professional knowledge: Advocates for their child within the mental health system.
Communication: Communicates with health professionals on a regular basis.	Financial: Provides some financial support. Legal: May have legal guardianship.	Mothering: Occasionally involved in the provision of physical and socio-emotional care when required.
The watchful bystander carer		
Focusses on a lower level of care		
Aspects of care		
Monitoring: Monitors their child's mental health status.	Housing: Lives at home or, In the community.	Professional knowledge: Occasionally advocates for their child within the mental health system. Provides advice for their child on mental health and recovery.
Communication: Communicates less frequently with health professionals.	Financial: Provides ad hoc financial support.	Mothering: Occasionally involved in the provision of physical and socio-emotional care when required.
The life coach carer		
Focusses on a minimal level of care		
Aspects of care		
Monitoring: Monitors their child's mental health status.	Housing: Lives in the community.	Professional knowledge: Coaches their child to take an active role in their recovery. Advocates for their child within the mental health system when requested.
Communication: Communicates rarely with health professionals.	Financial: Provides ad hoc financial support.	Mothering: Occasionally involved in the provision of physical and socio-emotional care when requested.

changes was used to construct a model of informed care provided by health professionals with dual roles as mothers of adult children with schizophrenia (Figure 1). The model of informed care shown in Figure 1 illustrates the processes involved in participants' roles as providers of specialized care. The mothers moved through their fluctuating roles as - the constant carer; the coordinator carer; the watchful bystander carer and the life coach carer.

Being a mother with a dual role as a health professional strengthened their capacity for interprofessional collaboration on an individual level and was collated into a typology of roles: the constant carer; the coordinator carer; the watchful bystander carer and the life coach carer. The aspects of the care provided within the informed care

model included: monitoring; communication; housing; financial/legal; professional knowledge and mothering (see Table 1). Table 1 provides a detailed descriptor of each of the elements of the modes of caring. Fluctuations in the use of each of the modes were influenced by the episodic nature of the illness as well as the availability and acceptability of health resources.

Representative excerpts from the participants' stories are provided to illuminate their oscillating roles as the: constant carer; coordinator carer; watchful bystander carer and life coach carer.

The constant carer

Within the model of informed care, the participants who were categorized as 'constant carers' provided the highest

level and intensity of daily support. Their children had frequent admissions to inpatient mental health units; had been recently discharged from the hospital; or had difficulty engaging with community mental health services. The mothers were involved in many aspects of their adult child's care. In addition to providing a home, they advocated for the rights of their children; monitored their medications, ensured they attended their appointments, and provided substantial financial support. Some had legal guardianship. As mothers, they were actively involved in the daily provision of physical and socio-emotional care.

For Hannah, her role as a health professional and mother had blurred. Her son, who at the time of interview lived at home, had developmental delays while in primary school; limited success in living autonomously; and frequent hospitalizations. She provided aspects of care similar to the professional care provided within residential healthcare facilities. Each day she administered his medications and provided a daily allowance in an attempt to minimize his use of tobacco. In this way she supported his mental health and prevented additional hospitalizations.

[He] actually did have his own apartment where we supported him, but every time he was discharged from the hospital pretty much, he came home... [A]fter the last discharge he'd shown no interest in being on his own, so he lives with us... I have a system... I give him \$20 in the morning with some morning medication, that's how I determine he's taken his morning medication. And then I give, well he has to ask for more [money] later in the day if he needs... He smokes way too much. That's one thing that we have some conflict over. But I mean, I realize it's not very productive, but I pay for his needs so that means I'm paying for his cigarettes... I have that extra burden knowing how harmful it is. No, I mean there's no point. He won't quit. I can fight with him every day but it's not worth it. (Hannah)

The coordinator carer

The mothers who were coordinator carers provided a moderate level of shared care for their children who lived at home or nearby. These mothers monitored their children's mental status and ensured they attended health care appointments. They communicated with the mental health team on a regular basis and used their professional expertise to advocate for their children. As mothers, they provided financial support in addition to individualized physical and socio-emotional support. Some maintained guardianship responsibilities.

The next mother's story highlighted the role of family members as care coordinators. Betsy had two children diagnosed with schizophrenia. Her eldest child suicided at home following a brief inpatient mental health admission. When her younger son became unwell a year later, she was keenly aware of the importance of being actively involved in his care. As a nurse, Betsy was cognizant of the role of person and family centered care in ensuring continuity of care. She was cautiously optimistic about the treatment currently provided for her son and explained why:

Now I have a doctor that has been very willing to work with me now, I guess it's working with him [my son] ... I also know if anything is to go wrong or whatever, I do know it's just a phone call, we're to phone the nurses and say, hey, when can he

see the doctor again. Because that's how we have been working now for, you know some time and we do have an open rapport... the doctor's nurse is very good. You know, but it took me how long to get where I am, and if he goes to whatever team, I mean he'll have a different doctor... So, you know, we don't know what the future holds. (Betsy)

The participants in our study supported their children while living in the family home or in the community. Some mothers tolerated substance use within their homes. For one participant who had strict rules about substance use, the consequence for breaking the rules was eviction. This did not alter any ongoing concerns for the family member's health and wellbeing. Irrespective of interpersonal conflicts and geographical locations, mothers like Barbara continue to play active roles in their children's lives.

I agreed for him to come back to live with me with some pretty strict conditions and one was not to use substances in my house, and I was saying it's okay, you can have a drink... Unfortunately, my silly boy, who was not supposed to be using substances, bought some drugs online and had them delivered to my house. I said well, you won't be able to live here anymore... So away he went... And, he was in the shared accommodation. I'd rung a few times, CAT [Crisis Assessment Treatment] team who were looking after him, because he deteriorated rapidly... I rang the treating team and said look, I'd really like to speak to the consultant [psychiatrist]. (Barbara)

The watchful bystander carer

The watchful bystander carers provided lower levels of care. Their children may or may not live with them and the mothers might retain some guardianship responsibilities. Additional aspects of shared care include monitoring their adult child's mental health. They rarely found it necessary to communicate directly with health professionals. Ad hoc financial support was provided, and their mothering relationship was maintained by the occasional provision of physical and socio-emotional care. They used their professional knowledge to provide advice on mental health and recovery.

There were three mothers who currently functioned as watchful bystander carers. Susan's son still lived at home and despite their close proximity, she respected his rights as an adult. Susan worked in the same health care facility where her son received treatment. She rarely found it necessary to discuss her son's wellbeing, but when she did, her communications with his treating team were unobtrusive.

I found a little glitch with the communication, with his medical team, was of course because he's an adult and I would have to get him to sign his permission for me to speak with his doctor. I've never done that; I've never had to do that. I think he's kind of settled with his illness but at first, he didn't want me speaking with his doctor... so, I had to kind of work around that. If I had a question or a concern, I would mention it to the doctor... They would just take that information and take it into consideration when they were looking at him during his next appointment (Susan).

The life coach carer

The life coach carers provided the least amount of shared care. They maintained an awareness of their child's mental well-being and rarely interceded. The participants seldom

had contact with health professionals and their children no longer lived in the family home. They sustained their mothering relationship by providing physical and socio-emotional care when requested and occasionally offered financial support. The participants used their professional knowledge to coach their children to take an active role in their own recovery.

Like many others, the next participant's adult child had a tumultuous first episode of psychosis. At the time of the interview, her son was attending university and was well on his road to recovery. Nevertheless, Mary was there whenever he needed her support:

He's working probably two, three, sometimes four days a week, and he's doing two units of uni, and he's managing pretty well. So, the big thing he does, you know is relapse prevention. He knows what he's got to do to stay well... We still support him a lot. You know, we were up there last weekend because the relationship he was in ended and he moved out. So, we came up to help and to just be there for him... You know it's that family support thing too, isn't it? You know how important that is. (Mary)

Discussion

Mothers of adult children with schizophrenia navigate a mental health system that does not always support them in their roles (Harrington, 2016) and they tend to have cultivated specialized parenting skills with minimal guidance from an already stretched healthcare system. This study aimed to develop an understanding of the caregiving roles of health professionals who are also mothers of adult children with schizophrenia. The findings suggest that participants experienced changes in their identities and roles when endeavoring to meet their children's dynamic and static needs for care both at home and within the mental health system.

This study differs from other research in the following contexts: it was international, and the participants were mothers and health professionals who were carers of adult children with schizophrenia. There were a number of similarities noted within research of health professionals who cared for relatives who were elderly (Ward-Griffin et al., 2015); admitted to the hospital (Carlsson et al., 2016; Giles & Williamson, 2015), or for their children with acute illnesses (Lines et al., 2015; Salmond, 2011). In mental health, Chesla (1991) identified distinct forms of caregiving provided for adult children with schizophrenia including engaged care, conflicted care, managed care, and distanced care, which expanded their mothering skills and focused on their interpersonal connections with their children. Blomgren Mannerheim, Hellström Muhli, and Siouta (2016) research described parental caregiving as a complex *mélange* of physical and socio-emotional care involving daily activities within an engaged parent-child relationship. Nevertheless, in both mental health care models and the aforementioned research, the participants were not identified as health professionals who were mothers of adult children with schizophrenia.

Mothers have lifelong connections with their children and possess detailed knowledge of their medical histories as well as their academic, social, occupational, and family

strengths. The participants were aware of early warning signs of relapse and could identify stressors which might precipitate deteriorations in health. They were a source of knowledge on previous mental health treatments and teams. Similar to the roles of case managers (Marfleet et al., 2013), they provided advocacy, care co-ordination and psychosocial support during relapses and transitions of care. Mothers provide flexible support and individualized care for their adult children for a lifetime. When mothers are no longer able to care for their adult children, health care providers will need to ensure that access to housing and support services, as well as ongoing psychosocial support from other family members and friends is sustained.

In summary, mothers with dual roles, expanded their knowledge, to become informed carers, while struggling to negotiate support for their adult children within the mental health system. Nevertheless, international mental health policies and legislation continue to emphasize the rights of people to receive healthcare, within the context of shared decision making and family centered care (Registered Nurses' Association of Ontario, 2015; Thornicroft et al., 2016; World Health Organization (WHO), 2007).

It is beyond the scope of this paper to recommend that health professionals begin to utilize the information in the informed model of care. Further research of its integration into practice by mental health nurses is proposed. The study acknowledges the participants' roles as *defacto* case-managers and suggests that their active inclusion in shared decisions might promote person and family-centered care; improve mental health outcomes; and facilitate succession planning.

Limitations

The study was limited to health professionals and mothers and wider recruitment to other family members might extend our understanding of the roles of carers and how to utilize their strengths. Another limitation was related to the inclusion of adult children diagnosed with schizophrenia, which might influence the generalizability to other enduring mental illnesses. Purposive recruitment of males who are health professionals would expand our understanding of the roles of fathers as carers.

Recommendations

Schizophrenia is an enduring mental illness with significant impacts on healthcare resources, individuals and family members. It is realistic to presume that nurses, as the largest component of health professionals, are currently involved and continue to be involved in care of their family members diagnosed with schizophrenia. Their roles and expertise have been unrecognized and unquantified to date. However, the provision of this model of informed care provides an insight into the heretofore unseen world of health professionals who are mothering their adult children with severe mental health issues. Further research is recommended to investigate the prevalence of this phenomena. Mental healthcare encompasses an interdisciplinary approach and the

recognition of family carers as informed stakeholders and partners in the healthcare team is a component of inclusive recovery-oriented care for people living with schizophrenia. It is further recommended that mothers with both professional and insider knowledge of schizophrenia become co-creators in planning future mental healthcare strategies.

Conclusion

Through their stories, the women revealed the differing modes of caring which they slipped between while responding to the needs of their children. Understanding their experiences might facilitate an understanding by nurses and other health professionals, of how their colleagues might be included in the evaluation of mental health care practice. The reader of this article might be empowered to integrate the findings into their clinical experience and develop a personal understanding of the lived experiences of their contemporaries.

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Conflict of interest

The authors declare no conflicting interests.

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Summary of relevance

Problem of issue

There is a paucity of research related to the dual roles of health professionals (nurses) caring for their own children with schizophrenia.

What is already known?

Previous literature focusses on the various modes of caring for adult children with schizophrenia as well as the experiences of nurses providing care for family members with physical health care needs within acute and long-term care settings.

What this paper adds

This paper highlights the ongoing various caregiving roles of health professionals (primarily nurses) who are mothers of adult children with schizophrenia. The modes of caring discussed within this paper are informed by a blend of mothering knowledge (knowledge of their child) and professional scientific knowledge (the discourses of the health professional).

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